

# The Caregiver

Newsletter of the Duke Family Support Program

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Fall 2006

## Co-Sponsored by

Duke University Center for  
The Study of Aging and Human Development  
N.C. Division of Aging and Adult Services  
Joseph and Kathleen Bryan  
Alzheimer's Disease Research Center

## Duke Family Support Program

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Subscriptions to this newsletter are available free to North Carolina residents. Call 800-672-4213.  
View this newsletter online at [www.dukefamilysupport.org](http://www.dukefamilysupport.org).

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## Alzheimer's Association Contact Information

### Eastern North Carolina Chapter

400 Oberlin Road, Suite 220  
Raleigh, NC 27605  
919-832-3732  
800-228-8738  
[awatkins@alznc.org](mailto:awatkins@alznc.org)  
[www.alznc.org](http://www.alznc.org)

### Caregiver Education Conferences

**Lumberton** (*Southeastern Agricultural Center, Hwy 74*), Nov. 8<sup>th</sup>  
**Edenton** Feb. 28, 2007

#### Morehead City

(*First United Methodist Church*) Oct. 19<sup>th</sup>  
To register, please contact Jody Riddle at (252) 638-3185 ext. 3015 or [jriddle@eccog.org](mailto:jriddle@eccog.org)

### Western Carolina Chapter

Main Office, Piedmont Region  
3800 Shamrock Drive  
Charlotte, NC 28215-3220  
704-532-7392  
800-888-6671 (24-Hour Helpline)  
[www.alz-nc.org](http://www.alz-nc.org)  
email: [info@alz-nc.org](mailto:info@alz-nc.org)

#### Mountain Regional Office

31 College Place, Suite D320  
Asheville, NC 28801-2644  
828-254-7363  
800-522-2451

### Help Us Spread the Word

If you know of others who would find this newsletter useful, please tell them to call toll-free for a subscription. *The Caregiver*, published twice a year, is free to NC residents and \$10 per year for those out of state. Contact Mary Trabert, Program Coordinator, 1-800-672-4213 or [mary.trabert@duke.edu](mailto:mary.trabert@duke.edu).

#### Foothills Area Office

260 1<sup>st</sup> Avenue NW, #218  
Hickory, NC 28601-4757  
828-267-7100

#### Triad Area Office

1315 Ashleybrook Lane  
Winston-Salem, NC 27103  
336-725-3085

### Caregiver Education Conferences

November 9, 2006, 7:45 p.m. – 4:00 p.m.  
Alzheimer's Association **22<sup>nd</sup> Annual Fall Conference: *Support for Today's Caregiver***  
YMCA Blue Ridge Assembly, 84 Blue Ridge Circle, **Black Mountain**

### 14<sup>th</sup> Annual Spring Education Conference The Many Faces of Dementia 2007: Issues, Trends and Perceptions

The Charlotte Convention Center  
March 22, 2007

Featuring: John Morris, MD, Karen Stobbe and  
Jennifer Zeitzer  
Phone: 704-532-7390 or 800-888-6671

[www.alz-nc.org/springconference](http://www.alz-nc.org/springconference)

The following are scheduled throughout our 49 counties – call for information:

- \* *Candlelight Reflections* on November 1
- \* Family, community and professional education programs
- \* Memory Walks

### Outside North Carolina

#### National Alzheimer's Association

225 North Michigan Avenue, Suite 1700  
Chicago, IL 60601-7633  
312-335-8700  
800-272-3900  
[www.alz.org](http://www.alz.org)

## **WHY FOCUS ALZHEIMER RESEARCH ON MILD COGNITIVE IMPAIRMENT (MCI)?**

**James R. Burke, M.D, Ph.D.  
Associate Professor, Medicine-Neurology  
Clinical Core Director, Bryan ADRC  
Duke University Medical Center**

### **Early Research**

The research community has learned much about Alzheimer's disease (AD) since the start of the Joseph and Kathleen Bryan Alzheimer's Disease Research Center (ADRC) 26 years ago. In the 1980's, genetics were not thought to play a role in AD and no treatments were approved for use. Researchers in the Bryan ADRC showed that one gene, Apolipoprotein E, contributes to the development of AD in about 50% of people with the disease. And now two classes of medicine are approved for symptomatic treatment of AD: cholinesterase inhibitors, like donepezil (Aricept); and NMDA receptor antagonists, such as memantine (Namenda). Unfortunately, a therapy to halt or cure AD remains elusive while the need for such a therapy grows. Currently, there are approximately 4.5 million people with Alzheimer's disease in the United States, but that number is expected to increase to 10 - 15 million by the year 2030 unless new treatments are found.

### **MCI: A New Target**

Not surprisingly, most AD research in the past involved studying patients with dementia. Now we know that dementia is a later stage in the disease process. A recent major change in thinking about AD has led us to focus on the earliest symptoms. AD does not begin with the disabling symptoms of full-blown dementia, but rather starts with the gradual onset of memory loss. Memory loss that is greater than expected for age, but not enough to interfere with normal activities of daily living is called mild cognitive impairment (MCI). People with MCI are at increased risk for AD, but not everyone with MCI will develop dementia. Right now we are not able to predict who will progress to Alzheimer's disease and who will not. However, it is hoped that therapies aimed at slowing or halting the progression of MCI will reduce the number of people disabled by AD.

Currently, the Bryan ADRC's strategic research target is MCI. Our long-term research seeks the major contributors to the development and progression of MCI. While we continue to emphasize genetics, we also collect information on medical and environmental risk factors that lead to AD.

## People Power

To learn anything meaningful from this research, we must follow a large number of individuals. We plan to evaluate and follow 200 people with normal memory and 300 people with MCI. These research volunteers will contribute DNA by donating a sample of blood. They will be asked questions about their medical and social history and medication use, and they will be examined yearly for signs of changes in thinking or changes on a neurological exam. All volunteer research participants in this study must have a research partner, a family member or close friend, who can provide reliable information about the person with normal memory or early memory loss. The research partner is a vital contributor to research because adult-onset memory loss is often accompanied by a gradual loss of insight into one's memory or thinking process.

We hope that many of our volunteer research participants will also choose to participate in the brain donation or autopsy program. Our research results will be much more useful if we can confirm our medical findings with an examination of brain tissue after death. Brain tissue from well-studied people who die with or without Alzheimer's, or with MCI, is an invaluable source of research materials for approved scientists both within and outside the Bryan ADRC. The ultimate aim in studying these volunteer research participants is to be able to predict an individual's risk of developing MCI and AD. **We must learn who is at greatest risk so we can ultimately offer them early treatment to delay or prevent MCI or AD.**



*Dr. Burke answers participant questions at the Duke Bryan Alzheimer's Conference panel discussion in April 2006. Drs. Steffen (Psychiatry) and Davis (Nursing) look on.*

## **The Challenge Ahead**

The great changes in the diversity of the United States population broadens our cultural experiences, but this genetic and social diversity also means that research findings in one group may not apply to others. MCI occurs in all racial and ethnic groups, but how MCI develops in different groups is unknown. Since no single research center can study all groups, Duke's Bryan ADRC works collaboratively with other federally funded Alzheimer's Centers following similarly studied groups of people with MCI. The National Institute on Aging-funded scientists have agreed on a common set of information that will be collected on all MCI and AD volunteer research participants. This information is stored with no names attached in a secure database so that each individual's identity is protected. All research centers may use the de-identified testing and history results from research volunteers for studies approved as worthwhile and important by a panel of expert scientists.

## **Reflecting Our Community**

Duke's Bryan ADRC is located in Durham County where 40% of residents are African-American. Historically, African-Americans have been under-represented in research. They don't participate in studies relative to their numbers in the population. To remedy this difference in participation rates and to make research findings relevant to the significant number of African-Americans at risk of AD or MCI, Duke's Bryan ADRC has made a commitment to increase the number of African-Americans participating in and ultimately benefiting from the results of Alzheimer's research. When Duke is able to combine information on people representative of Durham County with research information from other volunteers with MCI (e.g. Latino, Asian) from other Centers, we all benefit from an accelerated pace of meaningful research findings.

## **More than Memory**

Research based on yearly examinations of people with Mild Cognitive Impairment is not the only work of the Bryan ADRC. Our scientists study brain imaging and the processes involved in thinking and memory. Duke's Bryan ADRC scientists lead clinical drug trials and laboratory studies of human and animal models of disease. Most important, the Bryan ADRC remains committed to individuals living with all stages of dementia and their families. And our research goes on side-by-side with programs offering help and information for families.

## **Hope for the Future**

Once we understand what causes MCI, we will be able to identify individuals at greatest risk for it. Knowing that an individual will likely progress to AD will help us develop therapies to halt the onset of Alzheimer's and other dementias before an individual's symptoms interfere with his or her daily life. We appreciate the efforts of all of our

research volunteers and encourage all those who are interested in participating in this important work to contact us.

### How to Become a Duke Bryan ADRC Research Participant

If you are over 60 years old, live within a 60 mile radius of Durham and you are interested in volunteering for Duke Bryan ADRC Research, please call 1 (919) 416 - 5380 or toll free 1 (866) 444 - 2372.



Do you suffer from  
Alzheimer's Disease  
or  
have a family  
member  
who suffers?

Duke University Medical Center is conducting  
a Research Study Exploring the Effects of an Investigational Drug  
on memory function in Alzheimer's patients.

If you would like more information about this study, please contact:  
Dr. Burke at 919-684-5650 or  
Deb Heydt, Study Coordinator,  
at 919-668-2843

IRB # 5743



### Duke Needs Brain Donors for Alzheimer's Disease Research

The Joseph and Kathleen Bryan Alzheimer's Disease Research Center at Duke University Medical Center needs brain donors who are:

- *at least 65 years old*
- *mentally alert*
- *live within 100 miles of Duke*

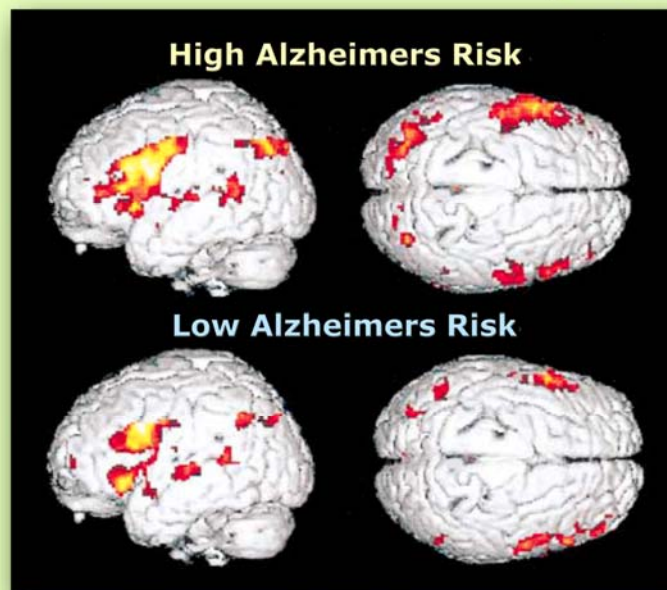
Arrangements for brain donation must be made well in advance of death. IRB #0182

Interested individuals should call Mari Szymanski, RN-C at  
(919) 416-5388 or toll free at 1-866-444-2372

## Volunteer for Research: Be Part of the Solution

### CALL FOR VOLUNTEERS - DUKE RESEARCH STUDY

#### **B**rain **R**esponses **A**ssociated with **I**ncreased Alzheimer's Risk & Healthy Aging



The BRAIN study is investigating patterns of brain activity associated with general aging and risk factors for Alzheimer's Disease (AD) in seniors.

You may be eligible to participate if you:

- are age 60-85
- do or do not have a family history of AD
- do or do not have memory complaints
- have no major life-threatening medical illnesses (cancer, etc.)

**Eligible participants will undergo free MRI scanning  
& brief screening tests of memory and thinking**

**For more information, please call:**

**(919)416-5380 or toll-free at 1(866)444-2372**

Supported by the National Institute on Aging (NIA) grant P50-AG05128  
Duke University Medical Center (#7672)



## Research Participation Options (continued)

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An investigation into the different coping abilities of African-American and Caucasian primary family caregivers of Alzheimer's patients is being conducted at Alliant International University located in San Diego, CA. Male and female caregivers are being recruited to answer seven questionnaires. Each questionnaire takes approximately 5 to 15 minutes to complete, which will take approximately 45 minutes to an hour of your time. Male and female NON-CAREGIVERS are also being recruited as a comparison group.

In order to qualify for the study as a PRIMARY family caregiver, you must be:

- 1) African-American or Caucasian,
- 2) Within the age range of 18 to 75,
- 3) 8<sup>th</sup> grade educated,
- 4) Caring for a family member with Alzheimer's disease who lives in your home, or you live in their home with them, or their home is 50 miles or less from where you live.

In order to qualify for the study as a NON-CAREGIVER, you must be:

- 1) African-American or Caucasian,
- 2) Within the age range of 18 to 75,
- 3) 8<sup>th</sup> grade educated,
- 4) A person who is not a caregiver of a person with a mental or physical disorder.

No cost or travel is involved. The questionnaires will be mailed to you, and you will return them using a self-addressed stamped envelope that will be provided. At the end of the study, there will be a drawing for two \$100 Wal-Mart gift cards: 1 for a caregiver and 1 for a non-caregiver (60 in each group). Contact **Annette Herron** toll-free at **1-866-324-3766**. (IRB# 946)

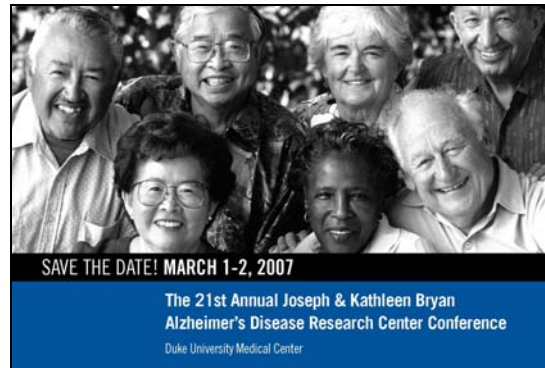
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Clinical Tools, Inc., a medical education company based in Chapel Hill, NC, is designing a new website for Alzheimer's disease/dementia caregivers. We are currently seeking participants to complete an online survey about their needs and interests to help us build the best website possible.

If you are currently the caregiver for someone with Alzheimer's disease or dementia – either you provide hands-on care or make decisions about care – then you may be eligible to participate. For more information, please e-mail study coordinator **Jonathan Wells** at [wells@clinicaltools.com](mailto:wells@clinicaltools.com). (Put “**Caregiver Study**” in the subject line.) Compensation will be provided (\$25).

This project is funded by the National Institutes of Health (Grant # IR43AG026227-01).





## SAVE THE DATE!

### Alzheimer's 2007: Strategic Directions in Research and Care

March 1-2, 2007

Durham Marriott at the Civic Center  
Durham, NC

#### Science and Practice

Join us for an exploration of the hottest leads created by combining population studies, genetics and clinic-based research. See the Duke Bryan Memory Disorders Clinic team "in action" as well as new workshops on creative approaches to care for people with dementia and their families.

#### **Tracking and Modifying Brain Aging**

Gary W. Small, MD

Professor of Psychiatry & Biobehavioral Sciences

Director, Memory & Aging Research Center

Director, UCLA Center on Aging

#### **Moderate to Late-Stage Alzheimer's Disease: Epidemiological and Clinical Insights**

Peter V. Rabins, MD, MPH

Professor and Director, Division of Geriatric Psychiatry and Neuropsychiatry

Johns Hopkins University

#### **Nutrition & Cognitive Change: Is It Possible to Prevent or Delay AD?**

Ronald G. Munger, PhD, MPH

Professor, Nutritional Epidemiologic Studies

Utah State University

**For:** Aging Services Administrators and Providers


Health & Social Work Professionals (long-term care, hospital, clinic, private practice)

(11.75 contact hours requested)

**People with Alzheimer's and their Families**

Visit <http://adrc.mc.duke.edu/news.html> or contact

Mary Trabert, Conference Coordinator, (919) 660-7510, (800) 646-2028, [mary.trabert@duke.edu](mailto:mary.trabert@duke.edu)

*Candlelight Reflections**to honor, hope and remember...*alzheimer's  association®nc family caregiver support program 

November is National Alzheimer's Disease Awareness Month as well as National Family Caregivers Month. The two Alzheimer's Association chapters in North Carolina are working with the N.C. Division of Aging and Adult Services, the Duke University Family Support Program and Bryan Alzheimer's Disease Research Center and N.C. Family Caregiver Specialists to hold Candlelight Reflections events honoring people and families affected by Alzheimer's disease and related memory disorders throughout N.C. on the evening of Nov. 1st.

**A Message from Dennis W. Streets, Director,  
North Carolina Department of Health and Human Services,  
Division of Aging and Adult Services**

"I am very excited about the upcoming 2006 *Candlelight Reflections* initiative – a partnership of the N.C. Family Caregiver Support Program and the N.C. Alzheimer's Support Network. This type of unified, collaborative approach will help raise public awareness and strengthen statewide efforts to support family caregivers of persons with debilitating conditions, including those living with Alzheimer's disease and related disorders.

**For more information about the event nearest you, please contact any of the following *Candlelight Reflections* supporters:**

- ✓ The *Candlelight Reflections* founders – N.C. Alzheimer's Association:  
Eastern North Carolina Chapter (919) 832-3732 or [www.alznc.org](http://www.alznc.org)  
Western Carolina Chapter (704) 532-7392 or [www.alz-nc.org](http://www.alz-nc.org)
- ✓ Duke Bryan Alzheimer's Disease Research Center African-American Community Outreach Program (AACOP) (866) 444-2372
- ✓ Your local Area Agency on Aging Family Caregiver Resource Specialists. A list can be found at [www.dhhs.state.nc.us/aging/fcaregr/fcjobs.htm](http://www.dhhs.state.nc.us/aging/fcaregr/fcjobs.htm) or call the NC Division of Aging and Adult Services at (919) 733-3983."

**Editor's note:** At press time there were over 50 scheduled Candlelight Reflections events throughout N.C. sponsored by the Alzheimer's Association, Family Caregiver Specialists at Area Agencies on Aging and the Duke Bryan ADRC African-American Community Outreach Program statewide visitors. For information about Raleigh and Durham events, see page 11.

# *Candlelight Reflections*



*to honor, hope and remember...*

Please join us at the location near you for this November 1<sup>st</sup> event honoring people with Alzheimer's disease and family caregivers.

**NC Museum of History, Bicentennial Plaza, Raleigh, 6:30 p.m.**

**The Eastern N.C. Alzheimer's Association's primary event.**

Contact: Peggy Smith (919) 832-3732 or (800) 228-8738; [psmith@alznc.org](mailto:psmith@alznc.org)

**Christian Faith Baptist Church, Raleigh, 6 p.m. – 7 p.m.**

Hosted by the Duke Bryan ADRC African American Community Outreach Program and the Eastern NC Alzheimer's Association African- American Outreach Program

Contacts: Rev. Henry L. Edmonds (919) 416-5385  
Rev. Dr. Cynthia Duarte (919) 460-7946


**Kirby Horton Hall at Duke Gardens, Durham, 6:15 p.m. -7:00 p.m.**

Hosted by the Joseph and Kathleen Bryan Alzheimer's Disease Research Center  
Duke University Medical Center

Dr. John Hope Franklin will be the Master of Ceremonies for a celebration with music, candles, photos, stories and more.

Contact: Roberta Wallace, MSW, LCSW (919) 668-2836

alzheimer's  association®

nc family caregiver support program 

## News and Notes

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### Alzheimer's Disease Fifth Leading Cause of Death for People Age 65 +

In 2003, age adjusted death rates for Alzheimer's disease (167.7 deaths per 100,000 people) surpassed death rates for diabetes mellitus (150.7 deaths per 100,000) and influenza and pneumonia (154.8 deaths per 100,000). Some of this increase has resulted from better reporting of Alzheimer's disease on death certificates.

Source: Federal Interagency Forum on Aging Related Statistics, Updated Statistical Report on Aging, NIA, July 10, 2006

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### Diet, Stimulant Stories Show Difficulty of Translating Scientific Research Into Advice

People expect science to provide clear-cut answers – especially on health matters -- but scientific research doesn't always yield simple conclusions, says a Duke University expert on science and popular culture.

"We think science has the answers, and we also desperately want answers when it comes to health," says Priscilla Wald, a Duke professor of English who studies the way that science is portrayed in the mainstream media and popular culture.

Two stories this year have contradicted accepted ideas about health and medicine. A new study indicated that eating a low-fat diet didn't significantly reduce the risk of some diseases.

Also, a federal advisory panel voted to recommend warning labels on stimulant medications used to treat Attention Deficit Disorder because they might increase the risk of strokes and heart problems.

People tend to see the results of scientific studies as all-or-nothing, and advertisers reinforce this by picking up findings and using them to promote products, she said. "We are looking for answers rather than being willing to accept complexity. We are looking for solutions rather than best chances," she said. "You have to live with uncertainty."

Conflicting information and advice in the media and in advertising also reflect the fact that the meaning of scientific research isn't always clear, even to the scientists themselves, she noted.

**"Journalists cannot get across the full complexity of any scientific information, any scientific study. Complexity is going to get edited out of a news story," she says.**

Duke News February 10, 2006, [www.dukenews.duke.edu](http://www.dukenews.duke.edu)

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### Scientists Discover New Frontotemporal Dementia Gene

Scientists have discovered genetic mutations that cause a form of familial frontotemporal dementia (FTD), a finding that provides clues to the underlying mechanism of this devastating disease and that may provide insight for future approaches to developing therapies. The mutations are contained in a single gene that scientists can now identify as responsible for a large portion of inherited FTD. A rare brain disorder, FTD usually affects people between ages 40 and 64 with symptoms that include personality changes and inappropriate social behavior. Published online July 16, 2006, in *Nature*, the research was funded by the National Institute on Aging (NIA).

The discovery builds on a 1998 finding of mutations in another gene that is responsible for a smaller proportion of inherited FTD cases. Amazingly, both the gene found in 1998 and the newly found gene were found on the same region of chromosome 17. The discovery appears to explain all the remaining inherited FTD cases linked to genes on chromosome 17 and may provide new insights into the causes of the overall disease process.

"This new finding is an important advance in our understanding of frontotemporal dementia," says NIA director Richard J. Hodes. "It identifies a mutation in the gene producing a growth factor that helps neurons survive, and it suggests that lack of this growth factor may be involved in this form of frontotemporal dementia."

FTD encompasses a set of early-onset brain disorders. While most cases are sporadic, an estimated 20 to 50 percent has a family history of dementia, according to the Association for Frontotemporal Dementias. FTD affects the frontal and temporal lobes of the brain. People with FTD may exhibit uninhibited and socially inappropriate behavior, changes in personality and, in late stages, loss of memory, motor skills and speech.

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## All on the Family

Anne J. Tate, 2006  
Charleston, SC

*My father was the comfort of my life, even when he had dementia.*

**Editors Note:** The following story about one daughter is taken from Anne J. Tate's 2006 thesis, All on the Family: Informal Caregiving in America, a paper submitted for her degree of Master of Arts in the School of Journalism and Mass Communication at the University of North Carolina at Chapel Hill. These excerpts are reprinted with the author's and the family caregiver's permission. This one family story suggests why NC's Alzheimer's Associations and the NC Family Caregiver Support Program chose to honor, hope and remember . . . with November 1<sup>st</sup> Candlelight Reflections events scheduled throughout the state for Alzheimer's and Family Caregiver Month. Regardless of where family members with Alzheimer's or related dementias live, it is all on the family and all about families who care.

Phyllis Immanuel, an administrative assistant, from Durham, NC, cared for her father, Alex Thomas, who had Alzheimer's disease, while he lived in three different nursing facilities over six years. Her mother, who had emphysema, lived in one nursing facility for the last nine months of her life.

Though she was one of six children, Phyllis took the lead in providing care, in part because she was close to her parents and wanted to do it, but also because she was initially the only one who was single and without family responsibilities.

### Finding a Home Away from Home

Alex Thomas had no choice about moving into a nursing facility. About fifteen years ago, Mr. Thomas saw a doctor (Dr. Redford Williams) from Duke Medical Center speaking about Alzheimer's disease on TV. He realized he had some of the symptoms being described. When Phyllis asked her father if he'd like to be tested, he said he believed he would, so she scheduled an appointment for him at the Duke Memory Disorders Clinic. She and her mother took him to the appointment.

It turned out that his hunch was correct. Phyllis's father was diagnosed with Alzheimer's disease in 1991. Two years later, a doctor recommended that Alex move into a nursing home after he had a heart attack.

*Ironically, Phyllis said, Mr. Thomas was in a room with his nephew, though he didn't always know it.*

The biggest problem at first was that he would wander, and one time he was found standing in the middle of a major traffic artery. Phyllis said he was looking for a train. Alex ended up living in three different facilities: two of those provided good care and one did not. Phyllis said he lost thirty pounds in the second home. There were signs of mistreatment and the nurses were surly. So Phyllis hired someone to stay with him until she could find the good place he lived for the last two years of his life. According to an email that Phyllis wrote, he was happy there. All in all, it was a very positive experience.

### Duty calls, even in the middle of the night

Though she was pleased with the quality of care, Phyllis could not simply sit back and let

the professional caregivers take the reins. Her mother still lived at home and her father had numerous health emergencies that required help from family.

In fact, Phyllis was called to the emergency room 11 times in a six-month span for both her mother and father. Her father was constantly falling and her mother often had complications of emphysema.

As her parents' power of attorney, she helped them plan their estate and adjust their insurance policies to accommodate her father's illness. Phyllis also arranged to have social services cover the costs of the nursing home when her father's retirement annuity no longer could, and in addition to visiting both parents, she went to monthly meetings at the nursing home to keep tabs on his care.

Phyllis reported that you are also taking care of yourself and dealing with your own grief and sadness during the whole experience. *My health was greatly affected while caring for my parents. However, I was simultaneously taking care of twin step-daughters who were in grief over the loss of their mother, a new house, a full-time job (which my boss allowed me to change to 35 hrs for a while) and my new husband. So how much the responsibilities of parental care affected my health percentage-wise is questionable.*

Phyllis also had relatives questioning her decisions. However, her husband and two step-daughters, who were 11 at the time she married their father, were extremely supportive. On Sundays they would go with Phyllis to pick up her father and take him to get hot dogs at Hardee's and ice cream at Baskin Robbins (two of his favorite things in life). *And they were just so sweet to him in helping him and doing things for him*, Phyllis said. *It was a very positive thing for all of them.*

The presence of siblings made a huge difference in Phyllis's situation. Though she took the lead in providing care and making crucial decisions, she could rely on her brothers and sister to help out in various ways. For instance, one brother would mow the lawn for their mother once a week. When her brother from out of state would visit, he would take their parents out to do fun things. Finally, they took turns going to the nursing home at varying times, ensuring that their parents were receiving adequate care.

#### Finding the strength to do what needs to be done

Phyllis regarded caring for her parents as a joyful good-bye. *I wanted to do it*, she said. *I just wanted it to be a positive experience. I wanted to end my relationship with my parents on a good note.* Her adoration of her father clearly affected how she perceived her role in care. *My father was the comfort of my life when I was growing up. He still was even when he had dementia. He was my comfort, and I didn't want any of that to be tainted by negativity.*

A daughters' support group at Duke also helped Phyllis. She was able to apply some of the lessons she learned from the group to her situation.

*One thing I learned is you have to allow people to do the things they can, and not expect them to do more.* For example, one night (December 13) Phyllis called one of her siblings from the emergency room to say their mother was there, and her sibling said, *I can't possibly come over there.*

Though rushing to the hospital in the middle of the night had been inconvenient for Phyllis, too, she said she was able to accept her sibling's response without resentment because of what she'd learned from her support group meetings.

#### Looking to God for answers

The desire to do God's will inspired Phyllis to take on the care giving role. *I think it's really*

*important to honor your parents. I think that pleases God. Phyllis also relied on her church for help. My church offered incredible prayer support during that time. There were folks who were always there for us, taking care of the girls when I needed to be at the nursing home.*

### The long goodbye: What it's like to lose someone after years of decline

Phyllis's father remained physically able. Phyllis even remarked how good he looked when she visited him the day before his death: *He was completely clean, shaven, in a freshly ironed shirt and pants. He looked wonderful. I walked in that room and I looked at him, and he didn't look a day over 65. He was 90. It was amazing.*

While Phyllis was there, the nurse had trouble finding his blood pressure and his oxygen level was extremely low. Her father was having visions of angels for a couple of weeks before his death.

Still, since they had not had a vacation for a couple of years, Phyllis went with her family to the beach that weekend. Phyllis said she was shopping with her stepdaughter when all of sudden she experienced a presence. She gasped and said, *Something happened.* Phyllis's cell phone rang a couple of minutes later, and she took it outside the store to hear. It was her favorite nurse who said, *I'm sorry to have to tell you this, but your dad died just a few minutes ago.* Phyllis realized what she felt was God's presence. Her dad had entered the presence of the Lord; simultaneously, Phyllis felt the Lord's presence. *It was a shock, but I was very calm. You know what? You're not going to believe this - but I had the deepest, strongest joy I've ever had in my whole life. The thing I kept thinking was, Daddy is with his Lord. For 55 years, he preached, he witnessed, he loved the Lord. And I knew he would never suffer again.*

Phyllis said she would do it all over again. Though she concedes it was difficult to watch her parents suffer, she was happy to take care of them. *I loved it. My parents invested so much in life; it was a joy to be able to give back to them. It was hard work, but it was so worth it. I don't have a single regret, because I did what I could do. I gave it everything I had.*



## Learning to Listen with My Eyes

Mary H. Trabert  
Chapel Hill, NC

When you can't use words anymore to tell me what you want, you still talk to me with your body. You move quickly when upset, slowly when calm, dreamily when content.

Your hands grasp for things – hold air – let go. I match your reach, mirror your movements, try to have a conversation. Look. Notice. See patterns in your gestures that guide me.

I listen to your gestures now.

I hear you.

*Inspired by a Sept. 8 movement workshop for caregivers hosted by the Health Arts Network at Duke (HAND), led by Liz Lerman, founding director Liz Lerman Dance Exchange.*



## The Symmetry Moves Me

Henry Walker  
Durham, NC  
July 23, 2006



yesterday was Mother's birthday  
and I didn't remember it in any conscious way,  
a teflon slipperiness to my thoughts  
that kept the idea from settling and sticking,  
I, who made myself be there with her,  
wherever she went in the deepening maze  
and distancing shadows of Alzheimer's,

until near the end it seemed to me Mother was still there,  
though "there" was far from "here,"

I knew Mother well when she was here  
all connected in shared word and twinkled eye,  
and I followed her as she disengaged and went further and further away,

the effort of each empathic visit exhausted me  
because, though I felt her still out there,  
I had to tap deeply into my reservoirs of hope and love  
and deny the doubt and avoidance that also called to me out of the mists,

now, as my granddaughter approaches a year and a half,  
mists clear for her, distances shrink,  
and I am amazed at how fully present and engaged she is,  
her self coming to us from place and distance I only guess at,

the symmetry moves me:  
Mother returns to the source  
and my granddaughter emerges, fully here, from that same source,

I remember Mother in who I am  
and how much I joy in a Little One  
coming fully onto a world I share with her.

*Henry Walker will read his 2003 "Still All There?" poem about his mother at the Durham Candlelight Reflections on Nov. 1, 2006.*

## Learning to Improve Early-Stage Information

Rachel Adelson, M.A.  
Raleigh, NC



Early in dementia, the right information can help with everything from lifting morale to getting treatment and arranging finances. This summer, for the certificate program in aging at UNC-Chapel Hill, I interviewed more than 20 people with a stake in dementia diagnosis and care. Lisa Gwyther, MSW, education director of the Duke Bryan AD Research Center, and Mary Altpeter, PhD, MSW, of the UNC Institute on Aging, guided my work. My goal, given the abundant excellent materials on dementia, was to define any gaps in the early stages.

Input from people with dementia, their families, social workers, health-care professionals and health educators prompted recommendations about the value of information, the need for more early-stage materials, and key sensitivities.

First, we can improve access to information and stress its central, beneficial role throughout the illness. From the start, professionals can *in writing* recommend reliable sources such as the Alzheimer's Association and federal ADEAR clearinghouse. Trained dementia educators could respond to changing realities by providing targeted information in stages.

We need to distribute more materials about the early stages and all forms of dementia. It's essential to discuss not only memory loss but the many other changes in thinking and daily life, and to explore the potential of cognitive rehab for prolonging independence.

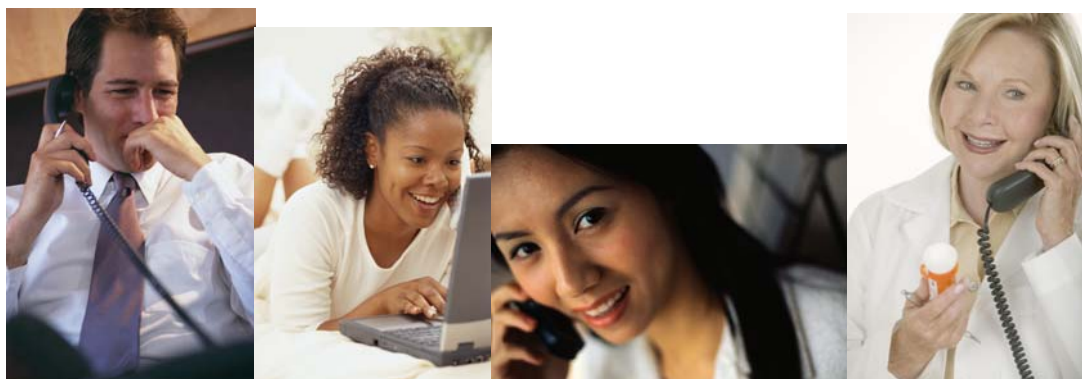
Informants were eloquent about the shock, grief, fear and anxiety of the diagnosis. To honor their early losses, we should avoid depicting the early stages as "good" or "easier" relative to the "bad" or "harder" middle-to-late stages. Information can address the unique emotional, functional and logistical challenges of each stage.

Informants also complained that oral and written information is mostly directed to family members; they want professionals to talk directly to people with dementia. Materials should reflect different family types and living arrangements, including the many people who live alone.

Stigma is a big problem. Perhaps an advocacy campaign could target stigmatizing media messages, such as TV programs that depict "senility" as laughable. To avoid shifting stigma to other vulnerable groups, we could replace, "It's not a mental illness" or "You're not going crazy," with more neutral terms such as "neurological problem" and "brain disorder." That still reassures people that their problems are not their fault, nor are they imagining or exaggerating them.

Finally, informants did not prefer any particular medium (print, video, Web...). They asked for dated materials and notification of new findings and treatments.

*Communications specialist Rachel Adelson writes often about neuroscience and cognitive aging.*



## TEN TIPS FOR TELEPHONE TALK WITH A PERSON WITH DEMENTIA

Roberta Wallace, MSW, ACSW, LCSW  
Bryan ADRC Memory Disorders Clinic, Duke Medical Center

**People with memory disorders want and need to stay connected to friends and family. But sometimes it is hard to know what to say. Try these tips and let us know if you have others. (Editor)**

1. Check with the person's primary caregiver, whether a family member or health care provider about:
  - Best time of day to call
  - Any topics which might upset the person
  - Topics or themes that sustain the person's good feelings about him/herself.
2. Don't rush into the purpose of the call. Allow plenty of time for the person to get comfortable and respond.
3. Try to keep calls short, but pleasant—a good neutral warm-up is the weather: "The blue sky today reminds me of our family picnics."
4. Do not question or quiz repeatedly. Remember, answers may not be accurate.
5. It's fine for the person to tell a favorite story, over and over again—memories get richer with the telling.
6. If s/he repeats the same question, give the same brief answer each time. Refrain from telling him/her that you just answered that question.
7. It is quite common for the person to be suspicious of those closest to him/her, and even to misinterpret what is seen or heard. Do not argue, explain or contradict beliefs. Listen, comfort and reassure. You don't have to agree.
8. Complaints about family, current living situation (nursing home) or physical ailments, should be acknowledged, "I'm sorry you are having a tough day"—you don't have to fix it or offer a solution. If you are concerned about something the person said, mention it to the family or care provider. Generally, they can clear up misunderstandings.
9. To avoid frustration or embarrassment be aware of the person's current abilities, otherwise they may feel they are not living up to expectations.
10. If s/he seems confused, upset or inattentive, promise to **call back later, and keep that promise.** Always end the conversation with an authentic and positive farewell.



## What Does a Good Visitor Look Like?

*The simplest act of human kindness for a fellow human being is more important than any refinement of the mind.* – William Sloane Coffin, Credo, 2004

### Notes from a family caregiver

Old Buddies: Otis, my father's best friend, would visit several times a week. He continued to treat my father as if he was still the same old Johnny. Otis had a construction business and sometimes had to go to Montross or Warsaw for materials. He would pick up Johnny just to take him for a ride. Johnny loved Otis. I have seen him turn his pockets inside out and say to Otis, "Man, I am broke, I don't have a dime." Otis would reach in his pocket and give him no less than fifty dollars even though [Dad] probably had forgotten the real value of money.

Mrs. Odessa/Mr. Donald: They came to visit frequently. They are very close friends of my mother. The three of them grew up together. They would come to see if my parents needed anything ...or to just visit and keep my father company and give my mother a break.

The grandchildren: My father loved children and they him. It didn't matter whose children from toddlers to teenagers. One 21-year-old started coming to our house when he was just a baby. [Once he could drive] he would take my father for rides. My father had a special love for his grand- and great-grandchildren. All of them treated him with respect when they came to visit. When his mind would slip, they would continue to talk and joke with him until he would come back around. When he died, every grandchild was at his bedside. Without being able to articulate or even think about it, they showed honor and respect by insisting no one sit in "his chair."

Other friends and neighbors: All of the neighbors and friends would watch out for him if he was outside. He loved to go to 7-Eleven where they would give him drinks and candy and other stuff he wasn't supposed to have. He also loved to usher in Church. When he would get confused, the other ushers would go and help him. They would even take him out-of-town when they were invited to usher at another church.

I believe having friends and family who visited him often and who interacted with him the way they always had in the past, along with the Aricept he was taking, really kept him functioning pretty well up until the end...

– Maxine Wilson, Caregiver

Holiday Visiting Tips: *A Message for the Faith Community and Friends of Alzheimer's Families*  
By Edna L. Ballard, MSW, ACSW and J. Whitney Little, Duke Leadership in an Aging Society Intern

## New Web Content



<http://eldercare.infopop.cc/eve> an AD-specific archive of posts and responses from angry caregivers, searchable by topic. You do not need to be a registered member to post. Click on the "Anger Wall" under "Alzheimer's Disease and Dementia."

<http://pubordering.cms.hhs.gov/maillinglist/> Order Medicare Basics: A Guide for Families and Friends of People with Medicare.

[www.afi.com/tvevents/100years/laughs.aspx](http://www.afi.com/tvevents/100years/laughs.aspx) American Film Institute's "100 Funniest American Movies of All Time," resource for laughter.

[www.alz.org/carefinder](http://www.alz.org/carefinder) new comprehensive, easy-to-use Web tool providing individuals with customized recommendations for care options (from home and community-based care to assisted living and nursing home care) and specific questions to ask care providers. For use by people with Alzheimer's and their families. \*\*\*\* **Highly recommended (Editor)**

[www.consumerreports.org/cro/health-fitness/nursing-home-guide/nursing-home-quality-monitor/0608\\_nursing-home-quality-monitor.htm](http://www.consumerreports.org/cro/health-fitness/nursing-home-guide/nursing-home-quality-monitor/0608_nursing-home-quality-monitor.htm) Consumer Reports Nursing Home Quality Monitor. Information available by state.

[www.dhhs.state.nc.us/aging/adultsvcs/afs\\_sa\\_inhome.htm](http://www.dhhs.state.nc.us/aging/adultsvcs/afs_sa_inhome.htm) The NC State/County Special Assistance In-Home Program for Adults (SA/IH) provides a cash supplement to those who qualify to help low-income individuals who are at risk of entering an Adult Care Home, and would like to remain at home.

[www.dhhs.state.nc.us/aging/adultsvcs/afs\\_special.htm](http://www.dhhs.state.nc.us/aging/adultsvcs/afs_special.htm) updated information on the NC Special Assistance Special Care Unit benefit for residents of special care units for Alzheimer's or related disorders.

[www.ec-online.net/Library/grief-loss/griefindex.html](http://www.ec-online.net/Library/grief-loss/griefindex.html) articles for families on dying, grief, caregiving, funerals, spirituality, support and coping.

[www.familycaregiversonline.com](http://www.familycaregiversonline.com) a Texas-funded family caregiver site with 16 on-line caregiver education modules.

[www.findaflushot.com](http://www.findaflushot.com) To locate flu shot offerings by zip code near you and family. (More about flu shots at [www.fullcirclecare.org](http://www.fullcirclecare.org) under "flu shot information.")

[www.merseyworld.com/moira/](http://www.merseyworld.com/moira/) an on-line gallery of David Lindsay-Coggins' paintings and poetry created to honor his wife, Moira, who developed Alzheimer's disease at age 50. Sponsored by the Glaxo Neurological Centre to mark National Carers Week in the UK.

[www.ncoa.org/content.cfm?sectionID=121&detail=1286#ad](http://www.ncoa.org/content.cfm?sectionID=121&detail=1286#ad) new selected bibliography on care of individuals with Alzheimer's disease from the National Interfaith Coalition on Aging (NICA).

[www.ncoa.org/content.cfm?sectionID=121&detail=1286#caregiving](http://www.ncoa.org/content.cfm?sectionID=121&detail=1286#caregiving) new selected bibliography on caregiving from the National Interfaith Coalition on Aging (NICA).

[www.project-compassion.lotsahelpinghands.com](http://www.project-compassion.lotsahelpinghands.com) an on-line volunteer coordination calendar for friends, families and neighbors assisting people in need.

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### Centers for Disease Control Exercise Recommendations for Older Adults

[www.cdc.gov/nccdphp/dnpa/physical/recommendations/older\\_adults.htm](http://www.cdc.gov/nccdphp/dnpa/physical/recommendations/older_adults.htm)

- moderate intensity aerobic exercise 3-5 days/wk for 30 minutes
- stretching exercise daily
- strength-building exercise 2-3 days/wk.

[www.cdc.gov/nccdphp/dnpa/physical/growing\\_stronger/index.htm](http://www.cdc.gov/nccdphp/dnpa/physical/growing_stronger/index.htm)

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### The Top Ten Things You Shouldn't Say to A Caregiver ...

*I thought it would be fun (and perhaps illuminating) to compile a list (a la Letterman) of the Ten Top Things You Shouldn't Say to a Caregiver. Things like ---"Why don't you just take a few weeks off and do something for yourself?" or "Why don't you just quit your job if you're overwhelmed?" or "You must be a saint." ...* email quote, Carol Levine, New York, New York

**Editor's note:** Tell us what you think. Call, write or email us your thoughts on "The Top Ten Things You Shouldn't Say to a Caregiver" and we'll share your contributions in our next issue.

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### Alzheimer's Acrostic

Angela Howard  
High Point, NC

Always  
Loving me  
Zealously  
Husband  
Endlessly  
Inquiring  
Mind!  
Eternally  
Remembering  
Some - one  
- place  
- times?

Hold on;  
hold fast;  
hold out.  
Patience is genius.

--- Georges-Louis Leclerc Buffon







## Have You Heard About?



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- Carlson E and Hsiao KB. (2006) The Baby Boomer's Guide to Nursing Home Care. Lanham, Maryland: Taylor Trade Publishing. 194 pp.
- Davidson, A. (2006) A Curious Kind of Widow: Loving a Man with Advanced Alzheimer's. McKinleyville, CA: Fithian Press.
- Laurenhue, K. (2006) Activities of Daily Living – an ADL Guide for Alzheimer's Care; Alzheimer's Basic Caregiving – an ABC Guide. [www.wisernow.com](http://www.wisernow.com).
- Mackenzie E and Rakel B. (2006) Holistic Approaches to Healthy Aging: Complementary and Alternative Medicine for Older Adults. New York, NY: Springer Publishing Company, Inc.
- Marella, D. (2005) Who Cares: A Loving Guide for My Future Caregivers. Sanford, FL: DC Press. 264 pp.
- Orr, AL and Rogers, PA. (2006) Aging and Vision Loss: A Handbook for Families. New York, NY: AFB Press [www.afb.org/store](http://www.afb.org/store). 240 pp. Available in paperback and on ASCII disk.
- Rosenbluth, R. (2005) Getting to Know Ruben Plotnick. Brooklyn, NY: Flashlight Press. Children's book
- Uetz, D and Lindsay, A. (2005) Into the Mist: When Someone You Love Has Alzheimer's Disease. Xlibris Paperback. 888-795-4274.

### Spanish Language HelpLine

The National Hospice and Palliative Care Organization (NHPO) is partnering with the National Alliance for Hispanic Health to offer a new help line, Cuidando con Cariño, Compassionate Care. Bilingual specialists answer questions about hospice, palliative care, grief and loss, caregiving and advance care planning. Toll-free 877-658-8896.

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*We are so busy doing the urgent that we don't have time to do the important. --- Confucius*

### Duke Family Support Program Donations

#### General Donations

Lisa P. Gwyther, MSW

#### In Memory of Bill Hamilton

Gail M. Cook

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Mary Jane Ellington

